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Supplemental Material

for

Removing Disincentives to Kidney Donation: A Quantitative Analysis

Short title: Removing Disincentives to Kidney Donation

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Supplemental Material

Appendix 1. NOTA Would Not Have to Be Amended

Neither the Department of Health and Human Services (HHS) nor the Department of Justice seems to object to reimbursing donors for their expenses as long as there is no payment for the kidney per se. Nor do they object to exchanging one kidney for another. Hence, all of our proposals to remove disincentives should be acceptable to both departments, and in fact can be administratively implemented by HHS. So NOTA would not have to be amended.

Indeed, that is what Delmonico *et al.* argue: *"Since covering expenses leaves living donors and the families of deceased donors in neither a better nor a worse financial situation than they would have been had they not taken part in the process of donating organs, there would be no need to modify NOTA's prohibition on paying for organs."*[7]

The argument that NOTA would not have to be changed runs as follows. NOTA states: *"It shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce."*

And

"The term "valuable consideration" does not include . . . the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ."[17] So clearly reimbursement for disincentives 1 and 2 are permitted by statute.

Moreover, the Mayo clinic web site says: *"It's illegal to be paid to be a donor. However, you can request that the recipient reimburse your travel, lodging, child care and other transplant-related expenses."* So reimbursement for disincentive 3 also seems to be legal.

Further, the Charlie Norwood Living Organ Donation Act of 2007[17] made kidney paired exchange legal, so reimbursement for disincentive 7 is also permitted.

Reimbursement for disincentives 4, 5, and 6 would seem to be within the spirit if not the letter of NOTA, so it is unlikely they would be subject to legal challenge. In that regard, it should be noted that there was no legal objection to kidney paired exchange from 2000 when it began to 2007 when it was made explicitly legal, despite the fact that the exchange of kidneys clearly involves "valuable consideration".

Nonetheless, it would be helpful to have the legality of reimbursement for all the disincentives clarified, as the Norwood act did for kidney paired exchange. Thus, we join Hays *et al. in ". . . seeking a memorandum for clarification from the Department of Justice about what is permissible under NOTA, and that 'reasonable payments' include all direct and incidental costs of the donor hospitalization associated with the recovery.*[6]"

However, should it become necessary to amend NOTA, that process is already well underway. In May 2016, Congressman Matt Cartwright introduced the Organ Donor Clarification Act that aims to clarify the legality of providing reimbursement to living organ donors.[33]

Appendix 2. Sick, Vacation, and Employment/Disability Insurance Pay (Disincentive 2): For some of the time off from work to donate a kidney, the donor receives income in the form of sick pay, vacation pay, and employment/disability insurance payments. The use of some of this pay for donation is a disincentive because, had this time/pay not been used for donation, it could have been used for other purposes. However, some of the time off from work for donation would not have been used for other purposes, so its use for donation is not a disincentive.

With regard to vacation time, we estimate most employees use almost all of their vacation time or are paid for the time they do not use. Therefore, if vacation time is used for kidney donation, it is a disincentive to donation.

Concerning sick time, we estimate about three-fourths of workers use all of their sick time, or are paid for the time they do not use. For these workers, the use of sick time for donation is the same disincentive to donation as with vacation time. However, we estimate the other one-fourth of workers do not use all of their sick time and are not paid for the time they do not use. Therefore, if they use their sick time for donation, it would just reduce their accumulated sick time, which otherwise would probably not be used. So this would be only a small disincentive to donation.

In the case of employment/disability insurance, it is not clear that its use for donation would preclude its use for other purposes, so its use for donation would not be a significant disincentive to donation. And the 10% of U.S. workers who are self-employed[40] bear all of the costs of donation since they do not receive any vacation or sick pay from an employer.

To sum up, we estimate the use of (1) all of vacation time, (2) three-fourths of sick time, and (3) none of the employment/disability insurance payments are disincentives to donation. Specifically, we estimate (based on the composition of these costs in Table 3 of Rodrigue *et al.*[15]) that two-thirds of the sum of sick pay, vacation pay, and employment insurance payments used for kidney donation is a disincentive to donation.

Appendix 3. Value of a Statistical Life (Disincentive 4): The consensus estimate of the value of a quality-adjusted life year is $200,000 (as discussed in Held-McCormick *et al*.[1] Supplement 1). Given this value, and assuming the average person in the U.S. is 38 years old[40] and will live another 46 years (according to the Social Security life expectancy calculator), then the discounted (at a real interest rate of 3 percent) present value of a statistical life is:

$$PV = C \{[1/r] - [1/(r \times [1+r]^{T})]\}$$

where: C = $200,000 per year

r = 0.03

T = 46 years

So PV = $200,000 {[1/.03] – [1/(.03 X [1+.03]^{46})]} = $4,955,090

which rounds to $5.0 million.

Many government estimates of the value of a human life are higher than this,[42] but they are influenced by political, and not just economic, considerations.

Appendix 4. Economic Loss from ESRD (Disincentive 6): To estimate the disincentive to kidney donation caused by a decrease in the living donor's long-term quality of life, we focus on the increased probability of developing ESRD because that is by far the most important negative long-term consequence of donation. The Organ Procurement and Transplantation Network (OPTN) [which is operated under contract by the United Network for Organ Sharing (UNOS)] has already taken steps to reduce this disincentive by giving those few living donors who later develop ESRD priority in receiving a kidney from a deceased donor. Although this process seems to be working reasonably well,[43] it does not completely eliminate the burden on living kidney donors from developing ESRD.

Consider a group of donors who donate a kidney at the average donor age of 43 and suffer kidney failure 20 years later. Two treatment paths are possible. First, about 75% of these donors will medically qualify to receive one (or more likely two) transplants from deceased donors (assuming living kidney donors who need a second transplant are again given priority in receiving a kidney from a deceased donor). Second, the 25% who do not medically qualify for a transplant will receive dialysis therapy.

The 75% of donors who develop ESRD and medically qualify to receive transplants experience a decline in their quality of life (QOL) from a normal 1.0 to 0.75 for the remaining 22 years of their life. (The last number, according to the Social Security web site, is the expected remaining lifetime of a 63-year old person. And we will assume it

also applies to a 63-year old living kidney donor who receives two transplants, but was healthy enough to donate a kidney 20 years before.) Therefore, again assuming the value of a quality-adjusted life year is $200,000, a donor who receives transplants will nonetheless suffer a loss of about $794,663 [= (1 – 0.75) X 22 X $200,000 X $(1/(1.03)^{11})$] where the average loss occurs in 11 years.

Now consider the 25% of living kidney donors who develop ESRD but do not medically qualify for a transplant and hence receive dialysis therapy. Instead of enjoying a normal remaining life of 22 years with a QOL of 1.0, which has an expected value of $3,178,654 [= 22 X 1.0 X $200,000 X $(1/(1.03)^{11})$], they will live only about 5 years with a QOL of 0.52. So the expected value of their life would decline to about $482,959 [= 5 X 0.52 X $200,000 X $(1/(1.03)^{2.5})$]. Subtracting the second value from the first, we conclude a living kidney donor who develops ESRD and receives dialysis therapy suffers a loss of about $2,695,695 (= $3,178,654 - $482,959).

Combining both treatment paths -- weighting transplants 75% and dialysis 25% -- we estimate living kidney donors who later develop ESRD suffer a loss of about $1,269,921 [= (0.75 X $794,663) + (0.25 X $2,695,695)] at age 63.

Although this loss is very large, Muzaale *et al*.[44] found the lifetime probability of living kidney donors developing ESRD was only 0.90% (i.e., just under 1%), much lower than the 3.26% for the general population. Moreover, since we assume these costs are incurred about 20 years after donation, we will discount them back to the time of donation at a real interest rate of 3%. Therefore, the total disincentive to kidney donation because of an increased risk of developing ESRD is about $6,328 [= 0.0090 X $1,269,921 X $1/(1.03)^{20}$].

Appendix 5. Expected Value of Donor's Kidney (Disincentive 7): The expected value of a donor's second kidney to a close relative or friend mainly depends on the following five factors:

(1) The value of a transplant to a recipient. Held-McCormick *et al*.[1] estimated that, at the present time when the average kidney transplant recipient receives only one transplant, the discounted present value of a transplant kidney to a recipient is $937,000. This reflects the longer and healthier life that a transplant recipient enjoys compared to being on dialysis therapy.

(2) As discussed in Appendix 4 above, the average lifetime risk of a person in the U.S. developing ESRD and hence needing a transplant is 3.26%.

(3) The average donor is 43 years old and (according to the Social Security web site) is expected to live another 41 years. So the donor's disincentive to donating a kidney now is that it could be available for a relation for slightly more than half of the relation's expected 79-year lifetime.

(4) The quality of a donor's kidney gradually decreases as a donor ages. The half-life of the donor's kidney (based on 10-year survival data) declines from 19.4 years at age 43 to 5.7 years at age 84. If these half-lives are normalized to 1.0 at age 43 (the age consistent with the $937,000 value of a kidney transplant), they decline to 0.29 at age 84 and average 0.65 over the whole 43-84 age range.

(5) As discussed in Appendix 4 above, we estimate there is a 75% probability that someone who develops ESRD will be able to medically benefit from a transplant from a living donor.

The expected value to a close relative or friend of a donor's second kidney is the product of these five factors: $937,000 X 3.26% X 41/79 X 0.65 X 0.75 = $7,728.

This result is based on the probability that a specific recipient will develop ESRD during the donor's remaining lifetime, which is 1.7% (= 3.26% X 41/79). But if the donor is willing to donate his or her kidney to <u>two</u> specific recipients, then the probability that one of them will need the donor's kidney will be twice 1.7%, so the disincentive will be twice $7,728. In general, the greater the number of specific people a donor would be willing

to donate their second kidney to, the more valuable that second kidney is to the donor, so the greater is the disincentive to donate it to someone else now.

What is the magnitude of this disincentive to the average potential donor? We assume the average donor is willing and able to give their second kidney to one specific person, so the disincentive is $7,728.

However, great uncertainty surrounds this estimate because the average donor may be willing and able to give their second kidney to more or less than one specific person. Also, the word "able" is an important modifier. Not all would-be donors are accepted by transplant centers, and not all accepted donors are medically compatible with a specified recipient (even with the help of paired kidney exchange programs). Moreover, a person receiving a kidney from a living donor, as in this example, will on average live longer than one receiving a kidney from a deceased donor. But the $937,000 value of a transplant to a recipient was calculated assuming the current average of kidneys from living and deceased donors.

Or more fundamentally, the donor -- instead of being concerned about the value of the donor's kidney if it is saved for a specific relative -- could be more concerned about the value of the government's promise to give priority to the relative in receiving a deceased donor kidney. The latter is likely greater than the former because, among other things, the specified recipient does not have to worry about the donor being accepted by a transplant center or the donor being a medical match for the recipient. The recipient knows the deceased donor kidney will already have been donated, and the OPTN allocation process will ensure the kidney is a close match for the recipient.

In any event, few kidney donors would make either calculation. They simply know they possess a kidney which may save a relative's life someday. And to remove that disincentive to donation, the government promises to give that relative priority in receiving a deceased donor kidney.

So the bottom-line question is: how much will the number of living donors increase in response to the government giving priority to a specified relative of the donor in receiving a deceased donor kidney? We are assuming the average donor would value both their own kidney and the government's promise to provide a deceased donor kidney at $7,728. Therefore, in response to the government's promise, donations from living donors would likely increase by 2,358 (= $7,728 X 11,517/$37,745) (using the 11,517 average response of living donors to the removal of $37,745 of disincentives shown in Table 2 of the main text). In the end, this seems like a reasonable assumption, albeit surrounded with much uncertainty.

Appendix 6. Priority Proposal Would Not Require an Increase in Government Spending (Disincentive 7):

The proposal that the government give priority to a specific relative or friend of the donor in receiving a deceased donor kidney in the future should that person develop ESRD would not require any increase in government spending. Rather, the full cost would appear to be borne by patients already on the waiting list for a deceased donor kidney, all of whom would be moved down one place if the donor's specified recipient needs a kidney. However, on average there is only a 1.7% chance (as argued in Appendix 5 above) of this happening, whereas there is a virtually 100% chance that a donor donating to someone on the waiting list now (or likely to be added to it) would remove a patient from the waiting list.

Indeed, waiting list patients would greatly benefit even though this policy would apply to the 5,811 per year living donors who currently (2017) donate their kidney without such a promise. We saw in Appendix 5 above that the removal by the government of this $7,728 concern-for-relatives disincentive, will likely induce an additional 2,358 donations by living donors. But it would add only 139 [= (5,811 + 2,358) X 1.7%] recipients per year to the top of the waiting list. Thus, the government could promise to give priority

on the waiting list to 17 (= 2,358/139) specific friends or relatives before it would harm those on the waiting list.

The size of this ratio provides some reassurance that patients on the waiting list would not be harmed by this proposal. For instance, even if the magnitude of the seventh disincentive were only one-fourth of our estimated $7,728, and the responsiveness of living donors to its removal were only one-fourth of 11,517/$37,745, the policy would still induce 147 (= 2,358 X 0.25 X 0.25) additional living donors. This is still larger than the 101 [= (5,811 + 147) X 1.7%] recipients per year who would be added to the top of the waiting list.

Some kidney diseases are inherited, such as ADPKD, ADIKD, APOL1-related kidney disease, and Alport's/thin basement membrane disease. People who have relatives or friends with these diseases would be more likely to donate a kidney now in return for a promise that the person with these diseases would be given priority for a kidney in the future. But the probability that an <u>average</u> donor's specific named relative or friend would need a transplant would likely remain well under 100%.

Appendix 7. Waiting List Patients Would Benefit from More Deceased Donors (Disincentive Facing next-of-kin of Deceased Donors): Every time a next-of-kin approves the donation of a kidney from a deceased relative, there is almost a 100% chance it will remove about 1.55 potential transplant recipients from the waiting list (because, according to Schnier *et al*.,[35] about 1.55 kidneys can be transplanted per deceased donor). But there is only a 1.7% chance that the specific named relative or friend will need a kidney transplant, moving everyone down one place.

Indeed, patients on the waiting list would benefit from this policy of moving a specific relative or friend of the next-of-kin to the top of the waiting list even though it would also apply to the next-of-kin of the 9,082 (= 14,077 deceased donor kidneys transplanted in 2017 / 1.55 kidneys per donor) deceased donors whose kidneys are currently donated

without such a promise. Indeed, this policy of giving a specific relative or friend of the next-of-kin priority in receiving a transplant kidney would likely add only 170 [= (9,082 + 938) X 1.7%] recipients to the top of the waiting list, far less than the 938 {= 14,077 X [(80%-75%)/75%]} additional donations it would likely induce as the next-of-kin approval rate increases from 75% to 80%.

Appendix 8. The Increase in Living Donors in Response to the Removal of Different Disincentives

There are four indirect sources of information about the percentage increase in living donors in response to the removal of different disincentives:

(1) Schnier *et al*.[35] found the U.S. NLDAC program of reimbursing low-income living donors a relatively small amount (equivalent to $3,122 in 2017) for travel and lodging expenses increased the number of living donor kidney transplants among participating transplant centers by 14% (shown in the first row of Table 2).

(2) In December 2017, New Zealand began compensating living organ donors 100% of their lost income for up to 12 weeks.[36] In 2018, the number of living donors in New Zealand increased to 84 from 69 in 2017, a 22% increase.[37] If the removal of the $5,118 loss-of-income disincentive in the U.S. produced a similar percent response, we estimate the result would be roughly as shown in the second row of Table 2.

(3) Halpern *et al.*[38] surveyed 342 riders on the Philadelphia transit system about whether they would be willing to donate a kidney to a person at the top of the kidney waiting list in return for various levels of compensation. The authors found (Figure 3) that for middle-income ($40,000-$60,000/year) respondents, increasing the amount of compensation from zero to $10,000 caused a 61% increase in the willingness to donate (as shown in Table 2, row 3).

(4) The State of Israel enacted a package of reforms in 2008 and 2012 with the same objective and similar methods as the changes we are now proposing for the U.S. The Ministry of Health stated: [39] *"The program is intended to protect the donor, both from the medical-health perspective and from the financial perspective, to avoid loss from lack of earnings during the period following the surgery, and to ensure the donor's future physical and mental health."* In response, the number of living kidney donors increased from an average of 67 donors per year in the 2003-2010 period to 222 in 2016-17, i.e., by 231%**.** If the removal of all $37,745 of disincentives in the U.S. produced a similar percent response, the result would be as shown in Table 2, row 4.

Further, if we extrapolate all four of these relationships (between the removal of disincentives and the percentage change in living donors) out to the removal of all $37,745 of disincentives, the estimates of the increase in the number of living donors would be as shown in the right column of Table 2.

For example, in the Schnier case, removing $3,122 of disincentives resulted in a 14% increase in living donors. So removing all $37,745 of disincentives might cause a proportionate 169.3% [= ($37,745 / $3,122) X 14%] increase in living donors. Since the initial level of living donors in 2017 was 5,811, the increase in living donors would be 9,836 [= 5,811 X 1.693] per year.

Similarly, in the case of New Zealand, removal of $5,118 of disincentives caused a 22% increase in living donors. So the removal of all $37,745 of disincentives would cause a 162.2% [= ($37,745 / $5,118) X 22%] increase in living donors. Given the initial level of living donors in 2017 was 5,811, the increase in living donors would be 9,428 [= 5,811 X 1.622] per year.

If we average the four results in the right column of Table 2, we arrive at our base case estimate of an increase of 11,517 living donors in response to removing all disincentives.

However, given the great uncertainty surrounding this estimate, we examined two alternative scenarios with donor responsiveness to the removal of disincentives of plus and minus 50% of that in the base case. This gives some idea of the wide range of outcomes that are possible.

Note that we assume the uncertainty surrounding the increase in living donors is symmetric around the base case, i.e., there is an equal chance the increase will be above the base case as below. Although some may think the lower alternative is more likely, Economics Nobel Laureate Garry Becker and his co-author Julio Elías have made the opposite case.[13] They argue (page 9 and figure 4) that as the removal of disincentives approaches the sum of the disincentives (i.e., the donor's "reservation price"), the supply of living donors will increase sharply. We have chosen to take an agnostic middle position and assume the risk is symmetric around the base case.

Appendix 9. Removing Disincentives Would Cut the Kidney Waiting List in Half in Four Years

An increase in kidney donations from living and deceased donors, in response to the removal of the disincentives to donation, would cause a rapid reduction in the waiting list for kidneys from deceased donors, as illustrated in Table A9-1**.** Column 1 shows gross additions to the adult waiting list in 2017 were 30,918, which was less than the removals due to kidney transplants and other factors, resulting in a net reduction of 2,973.[45]

However, if all disincentives to kidney donation were removed, donations from living and deceased donors would increase by 11,517 and 938, respectively, as shown in column 2. If the other key variables (gross additions to the waiting list and the "other removals") were not affected in the short run by removal of the disincentives, then the waiting list would decline by 15,428. Moreover, the waiting list would continue falling due to the greater number of kidney transplants, plus the 15% per year attrition of patients on the

waiting list as they die or become too sick to undergo a transplant operation or for other reasons. Indeed, the number of patients on the waiting list (92,685 at the end of 2017) would fall to half that level in about four years. On the other hand, as the waiting list shrinks, the criteria for admitting patients to the list would likely be relaxed, and the percent of newly diagnosed ESRD patients added to the list each year would rise above the current level.

Table A9-1
Annual Additions and Removals to the Adult Kidney Waiting List
(currently and after disincentives are removed)

	(1) **Current Situation** (2017)	**(2)** **Increase in Donations if Disincentives Are Removed**	**(3)** **= (1) + (2)** **Situation after Disincentives Are Removed**
Gross additions to waiting list	30,918	--	30,918
Removals from waiting list			
Deceased donor transplants	14,077	+938	15,015
Living donor transplants	5,536	+11,517	17,053
Other removals (attrition)	14,278	--	14,278
Net reduction in waiting list (removals minus gross additions)	2,973		15,428

Source: *OPTN/SRTR 2017 Annual Data Report: Kidney*, Tables KI 5 and KI 6.[45]

Appendix 10. What Would It Cost Taxpayers to Remove the Disincentives to Living Donors?

The top row of Table 3 in the main text shows the annual number of living donors before the disincentives are removed (5,811 in 2017). The second row shows our estimate of the increase in living donors in response to the removal of all disincentives. In the base case, this is 11,517 per year (the average estimate from Table 2). The low and high response cases are minus and plus 50% of this base case (5,758 and 17,275). The third row gives the total number of living donors per year after the removal of disincentives, which is just the sum of the two rows above.

The middle eight rows of Table 3 show our estimates of the total annual outlays by the government to remove each of the disincentives for all living donors. For instance, the total outlays to remove the travel and lodging disincentive for the 17,328 living donors in the base case is $54 million (= $3,122 X 17,328) per year.

Note that although the sum of the disincentives facing an individual living kidney donor is about $37,745 (see Table 1), the outlays by the government to remove these disincentives would be somewhat less. This is because the $7,728 of disincentive 7 could be removed by the government promising to give priority in receiving a transplant to a specific relative or friend of the donor should that person develop ESRD. Only the remaining $30,017 of disincentives would require an initial government outlay. Thus, in the base case, our estimate of the initial government outlay to remove all the disincentives for all 17,328 living donors is only a modest $520 million (= $30,017 X 17,328) per year. Even in the high donor response case, the outlays would be only $693 million (= $30,017 X 23,086) per year.

With regard to the second row from the bottom of Table 3, as long as the increase in living donors in response to the removal of the disincentives is greater than 326 per year (just 3% of the response in the base case), taxpayers would save money. [This can be seen from the relationship between net savings for taxpayers (NST) and the

increase in living donors (ILD) embodied in Table 3: NST = (0.116 X ILD) – 37.8. So when NST is zero, ILD is 326 (= 37.8 / 0.116) per year.]

Appendix 11. The Government Can Afford to Err on the Side of Generosity in Reimbursing Living Kidney Donors

Held-McCormick *et al*.[1] estimated a living kidney donor currently confers on society a net benefit of about $1,132,000. This very large benefit, compared to the small $30,017 initial government outlay, makes it unnecessary to extensively debate what should and should not be considered a disincentive. Unlike other government programs, where frugality is an indisputable virtue, the government can afford to err on the side of generosity when it comes to reimbursing living kidney donors, and the only consequences will be less suffering on dialysis for ESRD patients, fewer premature deaths, and greater savings for the taxpayer.

Appendix 12. Government Reimbursement of Disincentives Should Not Be Taxable

Note that removing the disincentives to kidney donation would not provide a net benefit to donors. It would simply remove a burden that is discouraging donors from generously helping a relative or friend. Therefore, government reimbursement for disincentives should not be taxable. Nor should it reduce any government welfare payments the donor may be receiving. The latter is especially important because the marginal tax rate for poor people receiving government assistance can easily approach or exceed 100%, i.e., poor kidney donors could lose government welfare benefits that equal or exceed the amount of government reimbursement for the costs of donating their kidney.

Additional References for Appendices

40. Pew Research Center analysis of data from the U.S. Census Bureau 2015

41. Hirth RA, Chernew ME, Miller E, Fendrick AM, Weissert WG: Willingness to pay for a quality adjusted life year: in search of a standard. *Med Decis Making* 20: 332–342, 2000

42. Merrill D: No One Values Your Life More Than the Federal Government. *Bloomberg*, October 1, 2017

43. Wainright JL, Kucheryavaya AY, Klassen DK, and Stewart DE: The Impact of the New Kidney Allocation System on Prior Living Kidney Donors' Access to Deceased Donor Kidney Transplants: An Early Look. *Am J Transplant* Volume 17, Issue 4, 1103-1111, 1 April 2017

44. Muzaale AD, Massie AB, Wang M-C, Montgomery RA, McBride MA, Wainright JL, *et al.:* Risk of end-stage renal disease following live kidney donation*. JAMA* 12; 311(6): 579-586, Feb 2014

45. Hart A, Smith JM, Skeans MA, Gustafson SK, Wilk AR, Castro S, et al.: *OPTN/SRTR 2017 Annual Data Report: Kidney*, Tables KI 5 and KI 6, February 2019